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In our ICU, we are faced with some challenging patient situations that really test one's ability to continue to carry out nursing interventions that we know in our heart, are causing the patient more harm. In the eight years that I have been a nurse in my Multi-disciplinary ICU, this case was by far, the most ethically challenging that I have ever had to care for in the role as the Attending Nurse. This lovely man, which I will refer to as J.A., is described by his family as being the most loving husband, brother, father, and uncle, who would go out of his way to help you in any way that he could. Mr. A. had been in and out of the hospital for the last four years and his admission to our unit would be his last fight. Often times, families express their grief by requesting life sustaining treatment that can no longer benefit the patient, and actually is burdensome and prolonging the patient's death. Unfortunately, after 50 days in our ICU, this was what ultimately happened with Mr. A., despite all of our best efforts to relieve him of his suffering.

J.A. was a 67 y.o male with a past medical history of pulmonary embolism, atrial fibrillation, insulin dependent diabetes, and chronic kidney disease. In 2002, he was diagnosed with renal cell carcinoma that eventually metastasized to his pancreas and lungs requiring extensive surgical procedures. In 2014, he had a lung surgery to excise his mets and developed acute respiratory distress syndrome requiring ECMO and a prolonged ICU stay. The family was told by the medical team during this time that he was very critical, and they did not think that he was going to survive. The family was persistent and expressed that the patient is a fighter and will make it through whatever challenge lay ahead. Much to the surprise of all the providers caring for him, Mr. A. recovered from this complicated hospital course and returned home with no further major-medical events for about 4 years.
In December of 2017, the progression of his metastatic disease was causing persistent pain that large doses of opioids managed at home were not relieving, and he subsequently underwent a right femur fixation, and then a resection of his proximal femur with prosthetic reconstruction in June 2018. His June post-operative course was complicated by an NSTEMI following a blood transfusion and needed to be transferred to an ICU for sepsis, pneumonia, small bowel obstruction, and delirium for two weeks. Mr. A recovered and then was discharged home for a couple weeks before being readmitted to the hospital with respiratory symptoms and quickly decompensated within days, requiring a transfer to my ICU with hypercarbic respiratory failure secondary to aspiration, volume overload, and renal failure.

It wasn't until about two weeks into his stay in our ICU when I began my ARN rotation and he became one of my primary cases to manage. On the first day that I read his chart and spoke with the nurses who had cared for him, I felt compelled to place an Optimum Care Consult because I truly believed that this man was suffering. When I first had the opportunity to meet Mr. A., he was just extubated for the first time, and he was visibly anxious. As soon as I walked up to his bedside rail he immediately grabbed my hand and

squeezed it tight. I had asked him how he was doing and he shook his head, as if to say that he was not doing good. I assured him that we are taking good care of him and we are trying to get him better. Mr. A. was having such a difficult time breathing that he couldn't engage in a conversation with me – I went into his room not expecting to see him in such distress and instead I immediately noticed a deep fear in his eyes. When I tried to end our conversation and walk away, he grabbed my hand tighter and I stayed, gently coaching him through some deep breathing. He seemed to relax somewhat, but I realized that this would be a recurrent occurrence, knowing the seriousness of his respiratory pathology. When I finally left the room, my heart was just aching. I was deeply concerned about the burdens of life sustaining treatment for Mr. A. – nurses that were providing direct care informed me that he made statements such as "DNR" and " I just want to be comfortable", and didn't want the breathing tube replaced, but when he was asked to repeat these statements in front of his family, he wouldn't.

Mr. A. was suffering from end-stage metastatic cancer with no further treatment options available, respiratory failure requiring multiple re-intubations, renal failure requiring continuous dialysis, challenging pain management requiring use of high dose opioids, and subsequent multi-organ dysfunction. On a daily basis, I would hover around his room for an opportunity to talk to any members of the multi-disciplinary team such as Renal and Palliative Care, to ask their opinion on his clinical status. Each member of the multi-disciplinary team felt that this man was suffering, but the family was in denial because he pulled through the unthinkable four years ago when he was on ECMO; they truly believe that he was going to fight even harder, despite his severely compromised state. After each conversation that I had with a member of the multi-disciplinary team, I would then go and spend time at the bedside with the patient. This became a daily occurrence – it was the only thing that I felt that I could do to understand truly his suffering and the significant amount of delicate care that he needed. Each morning, he was the first patient that I would lay my eyes upon and complete my own assessment so that I was prepared to speak to the family. I would have multiple interactions with the family, at different points throughout the day at the bedside, and ask them how they thought he was doing and they would continue to tell me, "he's a fighter", especially the patient's brother who seemed to be assuming the role of head of the family during Mr. A's illness.

Communication with the family became more and more of a challenge because a few members of the family were medical professionals. The daily plan of care was continuously interrupted with what the family felt was best for this patient, making it very challenging to do what was best for him – and at times would make threats about transferring him to another hospital. At times, the family would make statements in the room so that the bedside nurse could hear, criticizing the care that he was receiving, but when I would meet with them every day, they would tell me otherwise. With me, they would express their gratitude for all the care that we are giving him and make statements that he was in the best hands. Their behavior and comments were escalating, they started to request updates only from the Attending, they began splitting staff and having some of the Responding Clinicians speak to a niece who was a physician in Chicago, and it was at that point that I felt that we needed to get a hold of this before it was completely out of our control. On a daily basis, I had to garner the moral courage to talk with the A family, while also bearing

witness to Mr. A's suffering. It was an experience that required a great deal of strength and fortitude that was made possible through team support and a sense of recognizing through my clinical experience, the futility of these treatments and its impact on a vulnerable patient. In this situation, Mr. A was the patriarch of a large family with great financial means, yet, despite his leadership, this man was vulnerable to the family dynamic to the point of losing his voice.

I made the decision to call a team meeting to discuss this case and how we can best serve the needs of this patient while also respecting the family's concerns and wishes. All members of this patient's team were beginning to feel "beat up" by this family and it was bringing everyone to a place where their frustrations and anger was clearly visible. I suggested that we meet with this family on a regular basis with the multi-disciplinary team that included the ICU team, Palliative Care, OCC, and Social Work, to start building a line of trust with the hopes that they would see that we are advocating for what is best for their loved one. At this point in time, we were the biggest advocates for this patient and I felt that was extremely important. This poor man was suffering and I was beginning to feel personally responsible because I was that consistent member of the team that was seeing it from all perspectives, the patient, the family, the nurses, and other members of the team on a daily basis.

The moral distress of the care team around contributing to this man's suffering was so powerful that for each day that man laid in that bed, it became more and more of a challenge for nursing and members of the care team to hide their emotions when interacting with the family. As the ARN, I began to feel a personal load of moral distress. During most challenging patient situations on our unit, I am able to diffuse most of the burden of moral distress from the bedside nurse, but I felt in this situation, I was letting my nurses down. I had tried everything and yet, everyone was still hurting – the patient, the family, the bedside nurses, the team, and myself. These situations, which occur most every week in our ICU, provide "on the job nurse-advocacy training" in order to advance a plan of care that protects the patient from harm. It is one of the most important aspects of my role as the ARN and while I felt a great deal of moral distress, I still needed to advocate for this patient because every day that he lay in that bed suffering, was another day that we did not do right by him.

After multiple team and family meetings, team debriefings, and tears, we were finally able to protect the patient from further harm and invoked the MGH "Life Sustaining Treatment Policy: Do No Harm" and the patient was made a DNR/DNI. Initially the family made another request to restart continuous dialysis and the Renal team decided that it was not in the patient's best interest. The family was not in agreement with our decision and asked that he be transferred to another facility for a second opinion. Over the course of a few days, the care team was actively trying to facilitate a transfer to another facility at the family's request. One facility would accept the patient only if the limitations listed in the "MGH Life Sustaining Treatment Policy" were retained, in addition to others, and another medical center would accept him as full code and stated, "it will be a short code". Despite this, the patient was never stable enough to transfer and quickly decompensated and passed peacefully with his wife and his priest at his side.

To this day, whenever we have a challenging, ethical patient situation arise, everyone says that it can't be as bad as Mr. A. In my role as the ARN, despite what ethical challenges I face, I must look at every case individually and continue to ask myself, "are we doing what is best for THIS patient?" For Mr. A., I had to trust in the documentation of providers who had met with him in the past where he expressed that he wouldn't want a tracheostomy and that he wanted to be made comfortable. I had to trust in one of our physician colleagues who was called in for a second opinion about this case and expressed to us that in this patient's culture, decisions are not made by one person, we must respect the family as a unit. I had to trust in my team that no matter how hard this got, we were all going to continue to fight for this patient. With these challenging cases, I find that I can become vulnerable at times because I am looked at by my peers as someone who will help save our patients from suffering. I have come to learn that there is only so much that I can do, but I will do everything that I can to try to alleviate any suffering of my patient's, their families, and my team.

SAMPLE QUESTIONS:

Clinician-Patient Relationship

1. You did a wonderful job illustrating how you connected with Mr. A's family in organizing family/team meetings. What strategies did you use to connect with Mr. A? How did you ensure his voice was heard?

Clinical Knowledge & Decision Making

1. In your cover letter, you speak of Mrs. S., who had a known PFO and was s/p right pneumonectomy. How was it determined that right sided ventilation was what she needed? How did you know it was PFO vs. the recent surgery that was the patient's issue?

Teamwork & Collaboration

1. How do you build a team of services around a patient so that you don't feel like you are taking it on yourself?